

Long-Covid questionnaire: *Summary of initial data exploration*

Nearly 75% of adults completing the Long-Covid (LC) questionnaire indicated they were experiencing LC at the time of the questionnaire. Almost 20% of adults reported to have had LC in the past and 5% responded as a friend, family member or carer of someone that had experienced LC.

1. Experiencing symptoms of Long-Covid

Most respondents* (98%) experienced a combination of symptoms as part of LC. For nearly half of those this combination included up to six symptoms, but 6% reported as many as 13 or more symptoms. The most common symptoms people experienced were extreme tiredness (88%), problems with memory and concentration (78%), shortness of breath (69%) and joint pain (56%).

Over a third (37%) of people indicated they experienced feelings of loneliness and isolation during LC. Of those, 27% reported they received help in the form of counselling, referral to the post covid rehabilitation team or becoming part of a LC group. However, the majority (74%) of adults and all of the children did not receive any help with loneliness/isolation.

2. Living with Long-Covid: finding support and information

Overall, 62% of respondents sought information about LC. People relied on **online** sources (e.g., websites, social media, research studies), **professionals** in the health service (e.g., GPs, occupational therapists, LC support teams) or **both** to find information.

Based on the free text provided in the questionnaire, people with LC looked for:

- Information about **causes & symptoms**,
- Information on **how to cope with LC** and
- Information on **treatment** options.

Many respondents noted that the available information, either online or from professionals, “was limited”, “did not help” or only helped them “slightly”. Among those that did find the information helpful, it was the reassurance, validation and understanding of their symptoms/LC they found most beneficial. Just over 25% of adults, but none of the children, were able to access activities that aided recovery. Physical activity and mindfulness were the ones most frequently accessed.

Free text responses revealed gaps in information, barriers faced in finding information and support as well as suggestions on what would have been helpful.

a) **People need more and clear information on Long-Covid in one place.**

Respondents indicated that more, clear, and conclusive information on LC was needed. Those completing the children’s questionnaire, also reported the need for information and advice specifically around LC in children.

* The term respondents in this summary refers to both adults and children.

Ideally all this information should be centralised, so that anyone could be directed to this singular place by GP practices, professionals, peers, online links, social media posts or leaflets sent with positive test results.

b) People need support from professionals and peers.

Based on the questionnaire free text results, adults with LC symptoms gained many benefits from contact with peers (e.g., no longer feeling alone, sharing information and experience). However, no peer support groups were mentioned by those completing the children's questionnaire other than the suggestion that they would have been helpful.

People also expressed the need to be taken serious by their or their child's healthcare professional with quicker diagnosis, shorter waiting times and better follow-up care of people with LC.

3. Ways in which people with Long-Covid could be supported

In addition to the need for information and support, respondents specified elements and provided suggestions for what could improve the support of people with LC.

a) Pacing activity levels

For those experiencing LC while working or studying, it was mentioned that a balance was needed to maintain quality of life. Some experienced difficulties at work due to symptoms, others felt there was no energy left after working/attending school. Guidance on how to pace activity throughout the day, extra rest periods, home education, information on sleep hygiene, together with the use of activity diaries, could help to support people with LC.

b) Tailored exercises

While many acknowledged the benefit of physical activity and exercise, it was also mentioned that this should be built up slowly. Suggestions included: gentle muscle building exercises, exercises to help regain strength, physical activity for low energy, walking, singing, yoga, Tai chi, stretching and physiotherapy.

c) Techniques to help improve symptoms

Respondents referred to the need of information on breathing techniques and exercises, tinnitus, relaxation techniques, sleep hygiene, meditation to help improve symptoms and a diet that would not irritate the throat.

Alongside good nutrition and a varied diet, some respondents had also started the use of supplements and probiotics to help improve their symptoms.